

- VTDigger - <http://vtdigger.org> -

State looks to eliminate "payor of last resort" program for children with special health needs

Posted By [Alicia Freese](#) On November 19, 2012 @ 4:41 am In [Human Services, State Budget](#) | [6 Comments](#)



[1]

Photo by Hanza Soukup. Courtesy of Creative Commons/Flickr.

The Financial Assistance for Respite Rule has a benign-sounding name, but it's causing concern among those caring for children with special health needs.

That's because the rule actually eliminates the comprehensive cost-sharing program for caregivers.

The two-page rule nixes the \$700,000 payor-of-last-resort program, which is about 80 percent of the Children with Special Health Needs budget. It places the burden of paying deductibles, co-pays, and other costs back on families.

During a hearing on Nov. 15, distressed parents urged the Legislative Committee on Administrative Rules to reject the rule.

Laura Eddy, the parent of two daughters

with cystic fibrosis, told the legislators, "This is not about respite ... this is about eliminating care."

Breena Holmes, director of the Maternal and Child Health division of the Vermont Department of Health, which oversees Children with Special Health Needs, disagrees — "This is not another state program cutting vulnerable people. It's actually kind of the opposite."

The rule

As the name implies, the rule sets up a framework for families to receive "limited funding for short-term support and relief" from caregiving duties. But in the annotated version of the rule, it's clear that what has been crossed off far outweighs what's been added.

Children with Special Health Needs has traditionally acted as a payor-of-last resort for families without health insurance and for those with costs that fall outside the scope of their coverage on a graduated scale based on income.

These unmet costs include deductibles, co-pays, co-insurance, and goods or services that insurance and/or Medicaid don't consider medically necessary. The new rule proposes to phase out this financial assistance over the next year and then terminates it completely by January 2014.

Steve Brooks, operations director for Children with Special Health Needs, testified that there are fewer than 20 families that have neither Medicaid nor private insurance.

According to Brooks, 70-75 percent of payor-of-last-resort funds go to families with Medicaid and 20-25 percent go to families with private insurance. Some families have both public and private insurance. He said one-on-one financial consultations with the uninsured families revealed that some of them were, in fact, eligible for Medicaid.

But the parents who testified during the Nov. 15 committee meeting said this often isn't enough. Mark Sanborn said his family has private insurance and Medicaid, but when they traveled to

Texas for a specialized cranial surgery for his child, the out-of-state doctors didn't accept Vermont Medicaid. They would have had to foot 20 percent of the \$87,000 bill if Children with Special Health Needs hadn't stepped in to cover the cost.

Eddy said her family's private insurance and Medicaid still leaves them shouldering the significant burden of co-pays, deductibles, and the wages she and her husband lose due to the intensive caretaking demands.

Heidi Pecott-Grimm, a registered nurse and cystic fibrosis coordinator at Fletcher Allen Health Care, testified that nutritional supplements, Motrin, and other medication accompaniment often fall outside the scope of coverage.

Brooks said Children with Special Health Needs is equipped to work individually with affected families to explore other coverage options and secure alternative means of financial support. Still a consultation sounds like a paltry substitute for families reliant on CSHN as a payor of last resort.

Brooks noted that an increasing number of families face annual deductibles from \$3,000 to as high as \$9,000, and Holmes acknowledged, "The individual patient piece of this is awful."

Who else gets left out?

Nestled within the text is another key change: Children with Special Health Needs is, for the first time, defining its eligibility requirements. Though there was a general understanding that the program was intended for children, Holmes said, the lack of clear guidelines meant that in some cases people received services past the age of 21.

The new rule clarifies only children from birth to age 21 are covered, and it establishes income eligibility requirements for the first time. Now, only families that earn at or less than 500 percent of the federal poverty level will qualify for assistance.

Holmes said the 500 percent threshold is "not perfect," but, she added, it is more generous than most federal programs, which adopt a 150 percent threshold.

This change allows Children with Special Health Needs to focus resources on families with the greatest need, Holmes said, but it forsakes families that fall above that threshold and those over the age of 21.

Identity change for CSHN

The rule does not come as the consequence of dried up funding. The Maternal and Child Health division wants to retreat from its role as payor-of-last-resort so that it can redirect money to more comprehensive "systems-based" services.

Brooks says Children with Special Health Needs was never intended to be a payor and the process for handling claims is riddled with inefficiencies and is carried out by hand rather than electronically.

Both he and Holmes pointed out that Vermont is an outlier in this regard— "We are the last state that does direct service ... it's not a natural fit for Children with Special Health Needs, " Holmes said.

Funding for the Maternal and Child Health division of the Public Health Department dates back to 1935 when President Franklin D. Roosevelt first set up federal funding for women and children is part of Title V of the Social Security Act. States have to pitch in with a matching grant. Children with Special Health Needs' total budget in fiscal year 2011 was \$883,600 and nearly 80 percent of this was spent on payor of last resort expenses.

What does CSHN propose to do with the roughly \$700,000 that will be freed up if they nix the payor of last resort program? A number of things, Brooks said.

They would broaden the eligibility requirements to incorporate children with diabetes, asthma, vision impairments, and cancer, among other afflictions, into the program.

They would expand the current respite program, which Brooks identifies as "one of the greatest unmet needs" of families. Brooks said they would also bolster their care coordination work, which helps families to navigate the health care system, and a program that assigns medical social workers that assist pediatric practices that serve children with special needs.

Proposed on the sly?

Holmes describes the rule drafting as "a five year process with family engagement, Vermont Family Network engagement, lots of stakeholders, working with doctors of families, and 20 drafts."

Brooks said Children with Special Health Needs sent letters notifying all 1,800 families who have at one point benefited from the payor of last resort program of the proposed changes.

But the parents who testified during the Nov. 15 committee meeting offered a notably different impression of the process. Laura Eddy characterized the manner in which Children with Special Health Needs introduced the rule as "dishonest and deceitful"; Mark Sanborn, another parent, said he thought "it was done arbitrarily."

In a memo to committee members, Karen Schwartz, executive director of Vermont Developmental Disabilities Council, asked that the rule be rejected on the grounds that CSHN had failed to maximize public input and created confusion among families by lumping the respite rule, the eligibility definition, and the elimination of the payor of last resort program into a single rule.

The Legislature's take

After hearing a string of highly emotional testimonies, the Administrative Rules committee concluded that the rule needed more deliberation and will likely be brought before the entire Legislature in the upcoming session.

"There is no way I'm going to vote on this today," Sen. Diane Snelling concluded.

Rep. Richard Marek, chair of the Administrative Rules committee, suggested the Legislature may be willing to pony up more money to enable Children with Special Health Needs to carry on as payor of last resort, but Brooks was hesitant.

When Marek asked Brooks to think about "what number would you need from the state end of the equation," he responded, "we could come up with a number," but "I would question very strongly if Children with Special Health Needs is where that number should go."

"I would love if there was a pot of money set aside for these extremely vulnerable families," Holmes said but, like Brooks, she stressed that Children with Special Health Needs was not cut out for this.

Holmes didn't want to suggest a specific agency that could act as distributor of these funds, but she said family network agencies could have the capacity to carry out this role.

6 Comments To "State looks to eliminate "payor of last resort" program for children with special health needs"

#1 Comment By [Ann Raynolds](#) On November 19, 2012 @ 7:25 am

Thanks to a good legislative committee, the confusions inherent in this move will not go into effect. In the last paragraph Holmes mentions "family network agencies" but without specifying who & where these are.

I agree that too many changes are mixed into this proposal, such that parents are frustrated and the public, me, confused. There may be some good points that can be made, but respite – respite – respite must be saved!

I just attended a Harvard symposium on Autism this past weekend and the effects on families was stressed over and over, as well as statistics provided about the loss of jobs, disintegration of marriages and ostracism of parents of special needs children. We can not abandon these families.

#2 Comment By [Sheryl Rapee-Adams](#) On November 19, 2012 @ 8:13 am

Whoops, that's Senator *Diane* Snelling.

"There is no way I'm going to vote on this today," Sen. Diana Snelling concluded.

#3 Comment By [Alicia Freese](#) On November 19, 2012 @ 9:36 am

Thanks for pointing this out, Sheryl. The typo has been fixed.

#4 Comment By [Donald Kreis](#) On November 19, 2012 @ 11:17 am

Many, many thanks to Alicia Freese for covering this important story. As the father of a child with cystic fibrosis, I am confused and dismayed by the direction the Shumlin Administration has taken on this issue. In particular, I do not understand why a Governor who hopes the signal achievement of his administration will be single-payor healthcare and universal health coverage would throw under the proverbial bus so many stressed families that are raising children with chronic illnesses. It just doesn't make sense. Regrettably, Steve Brooks of the Department of Health apparently decided it wasn't convenient or useful to return the call I made to him in quest of enlightenment.

Let me be clear — my daughter and my family have not received any help from the CSHN program. I do not believe we qualify. But I am heartsick nonetheless. Why? Because I happen to know that in a good year — no hospitalizations or other crises, just routine care — it costs a cystic fibrosis patient \$88,000 a year in healthcare costs (and that sum is in 2010 dollars — the source being the Cystic Fibrosis Foundation). I also know from personal experience that for people with CF the difference between good health and lousy health, which means the difference between a good long life and a miserable short life, is having precisely the stuff that will fall through the cracks for some families if the Shumlin Administration succeeds in gutting the CSHN program in the manner contemplated.

May I offer an example? Vitamins. My kid has to take special vitamins that cost hundreds of dollars a year. They are prescribed by my daughter's CF physicians. But the health insurance gatekeepers can't wrap their brains around reimbursing for vitamins — so, either you pay for them out of pocket or you go without. I cannot stress enough — this stuff makes a difference, and in a longterm sense because compromised healthcare in childhood makes for short and unhappy adulthoods.

I apologize to families dealing with other chronic illnesses for belaboring the CF-specific issues. Cystic fibrosis is tough but it is by no means the most challenging chronic illness that a family could confront. I can only imagine how tough it will be for families who face illnesses with more widespread impacts — cognitive impairments, limitations on mobility, etc. When I am not sad, I'm shocked.

Heartfelt thanks to the Legislature's Administrative Rules Committee for listening to the testimony and flagging this issue for further inquiry when the Legislature reconvenes. Caving to the Department of Health's recommendations would have been an easy course of action. But what the Department is trying to do will cause suffering and is inimical to the public policy of Vermont — the compassion that Vermonters expect of their government.

#5 Comment By [rosemarie jackowski](#) On November 19, 2012 @ 11:42 am

Is this one more reason we need SinglePayer?

If Iceland can do it with a population about half of Vermont's – and if larger countries can do it – what is wrong with us? (Too many opposed to Single Payer use the invalid 'size' argument.)

If VT legislators cannot get this done – they should seek the advice of Canadians... and fire the GMCB. We need Single Payer now. Tomorrow is too late.

#6 Comment By [Dan Feliciano](#) On November 21, 2012 @ 1:00 am

What problem is the state trying to solve? It seems to me that the state is clueless about the actual problem they're trying to solve and have lumped in a bunch of special interests together to write / create a new ruling to satisfy the special interests.

Single payor? Please! The state can't figure out how to write a decent bill nor figure out how to provide services and people think we would be better off with a Single Payor system.

Article printed from VTDigger: <http://vtdigger.org>

URL to article: <http://vtdigger.org/2012/11/19/state-looks-to-eliminate-payor-of-last-resort-program-for-children-with-special-needs/>

URLs in this post:

[1] Image: http://vtdigger.org/vtdNewsMachine/wp-content/uploads/2012/11/3710131195_74d0115158.jpg

Copyright © 2011 VTDigger. All rights reserved.